

My Implant Journey

A Dream coming true

by
Chris Rawlins

Introduction

I started writing this account of ***My Implant Journey*** to document what I went through in the process of being Implanted with the Cochlear device and fitted with the Cochlear speech processor.

As I progressed I found that there is not any real instruction manual given before starting out so decided to try to add more information.

My hope is that my story may help others understand the process, what to expect and how they may be affected.

I am sending this to the Implant specialists and audiologists for their use if they deem it worthy of passing on to clients.

Please feel free to pass it on to anyone that may benefit.

My Implant Journey is long, sometimes very rough but it is ***A Dream Coming true.***

It is now a lifelong Journey

My Implant Journey

This is my story.

I am a 65 year old man who lives in Broken Hill, 500km from Adelaide and 1200km from Sydney.

A little about my past hearing.

Living in Broken Hill, I worked underground mining in a very noisy and humid environment that wasn't always conducive to earplugs or earmuffs and so I was doing damage to my hearing.

In the 1980's I went to see an ENT Specialist about my right ear.

He ordered Xrays that showed calcification to the middle ear bones that he said can be fixed any time.

When my right ear stopped hearing I blamed it on the calcification & thought I can get that fixed later.

In 1999 my wife & I went on a holiday to Cairns.

Driving along it seemed as if the car windows were down with the vibrations I was hearing.

On return home I went to my doctor whom sent me off to the ENT Specialist in Adelaide.

The specialist had scans done and diagnosed a Cholesteatoma in my right ear that had eaten through my scull into the brain cavity and was now pushing my brain up.

An urgent operation was needed to remove the problem.

During the operation, a Trans Medial Petrosectomy was performed.

The middle ear was ruined, the balance organs were destroyed but the Cochlea was still intact.

It took years to get over the palsy that was a direct result of the operation.

The ENT specialist also diagnosed Industrial Hearing loss in my left ear.

After more hearing tests I was fitted with a hearing aid.

I coped very well with my hearing and was involved in community projects.

In 2010 I attended a Hearing in the Hill conference where I met Professor WPR Gibson from the Sydney Cochlear Implant Centre.

The Prof, gave a lecture on implants and introduced 7 implantees who mixed socially and described their experiences.

I thought, this is for me ***I want one.***

In 2013 I went to the Syney Cochlear Implant Centre to find out more. Professor Gibson told me that it was too dangerous to implant the right ear as the facial nerve had been exposed in 5 places. He would not implant the left ear as the hearing was still too good. I came home disappointed but still comfortable that I could cope.

I was under the care of Australian Hearing who kept my hearing aid adjusted and supplied batteries.

Then came a rapid deterioration in my hearing. I was not coping well. A new more powerfull hearing aid was supplied but I was still having problems.

On one visit to the Australian Hearing Audiologist I said how frustrated I was that I could not cope. A hearing test was done and the Audiologist sent a letter to my GP recommending a visit to my ENT Specialist. I cannot fault the care and assistance I have received from the Australian Hearing Staff in Broken Hill.

At this point I was no longer communicating with family and friends, old work mates were dismissed or avoided and my wife was a constant cause of frustration because I couldn't communicate. I had become a Facebook & forum junkie as hearing was not needed there.

I went to Ent Surgeons at Memorial Hospital, Adelaide where hearing tests were done. On seeing the specialist I was told that my hearing was so bad she was referring me to the South Australian Cochlear Implant Centre (SACIC) for assesment. The specialist ordered CAT Scans whilst in Adelaide. I had to wait three months due to various factors.

At SACIC I met one of the team of Audiologists who conducted tests and explained the procedures. She said I qualify for an implant. We discussed my options and It was explained that it may benefit me to get my left ear implanted due to the fact that my right ear had not heard for about 20 years and that Professor Gibson had deemed it too dangerous to impant the right ear.

That same day I went to see ENT Surgeon Michael Schultz who is also a SACIC Surgeon. On reading the scans, Michael said he could implant the right ear. The worst ear being the Surgeons preference. Michael wanted MRI Scans so he could inspect what was left of my cochlea and to make sure an Implant would be viable.

I was so excited that I was getting somewhere, and that I may be able to communicate again.

On 26th of July 2017 I was admitted to Memorial Hospital for my Implant operation. The hardest part was waiting 5 hours to go into theatre. It's a very busy hospital with seven operating theatres working around the clock. At 5pm I was taken into theatre for my procedure.

I don't know how long the operation took but my wife said the Surgeon phoned her at 7.30 to say he had implanted my right ear and I was progressing well.

Due to possible facial nerve problems associated with my previous operation to remove the Cholesteatoma, I was taken to the Critical Care Ward.

On waking I was given very good care by the most friendly team of nurses you could ever meet. Nothing was too much trouble for them.

I was up to the toilet 4 times during the night and had to be disconnected from the monitors and drip each time.

I suffered no dizziness, very little pain, no sickness but a fair bit of discomfort.

On Thursday morning the Surgeon gave me permission to leave hospital after having X-rays taken of the Implant.

Sitting at the Radiology department and a very loud hum went through my head. Immediately after I could hear what was going on around me.

My theory is that the Implant excited the Auditory nerve and woke that part of my brain.



I was discharged from the hospital to return to our accommodation.
On the Friday we returned to Broken Hill by car.

On 3rd August, I saw the Surgeon for a Post Op check up and the staples were removed.

Much more comfortable now.

Hearing test showed my hearing had returned to the low level of before operation.

Switch on.

I have several switch on appointments of 60-90 minutes duration, over a period of 4 weeks to foster best hearing outcomes during this early period and to support in adapting to electrical stimulation.

What do I expect ?

The SACIC Audiologists have tried to keep my expectations low so that I am not overly depressed if I cannot hear for some time.

I want to get my life back and enjoy music, nature and most of all my Family.

SACIC have contacted me with various options for fitting including the Cochlear Kanso and Nucleus 7 speech processors.

I have opted for the remote Kanso at this stage.

It is now two weeks since my Implant Operation.

The incision has flattened out and scar is hardly visible.

My scalp where device is located is only a little tender but I can rub my head without pain.

I am getting bouts of tinnitus after sleeping but the hearing aid in my left ear seems to overcome that. I can still feel the “ buzzing “ though.

South Australian Cochlear Implant Centre Switch on & Mapping

Switch on and Mapping session 1.

We were taken into a room by the Audiologist who chatted and explained the procedure.

A test was done to find out how many electrodes were working on the implant. I had all 22 working so all good.

The first step was to fit the right strength magnet to the speech processor. Too strong and you get sores where the magnet sits. Too soft and the speech processor falls off.

Then my input levels were set.

First we went through the sounds to find the lower levels that I could hear.

Next step was the upper levels that I am comfortable with.

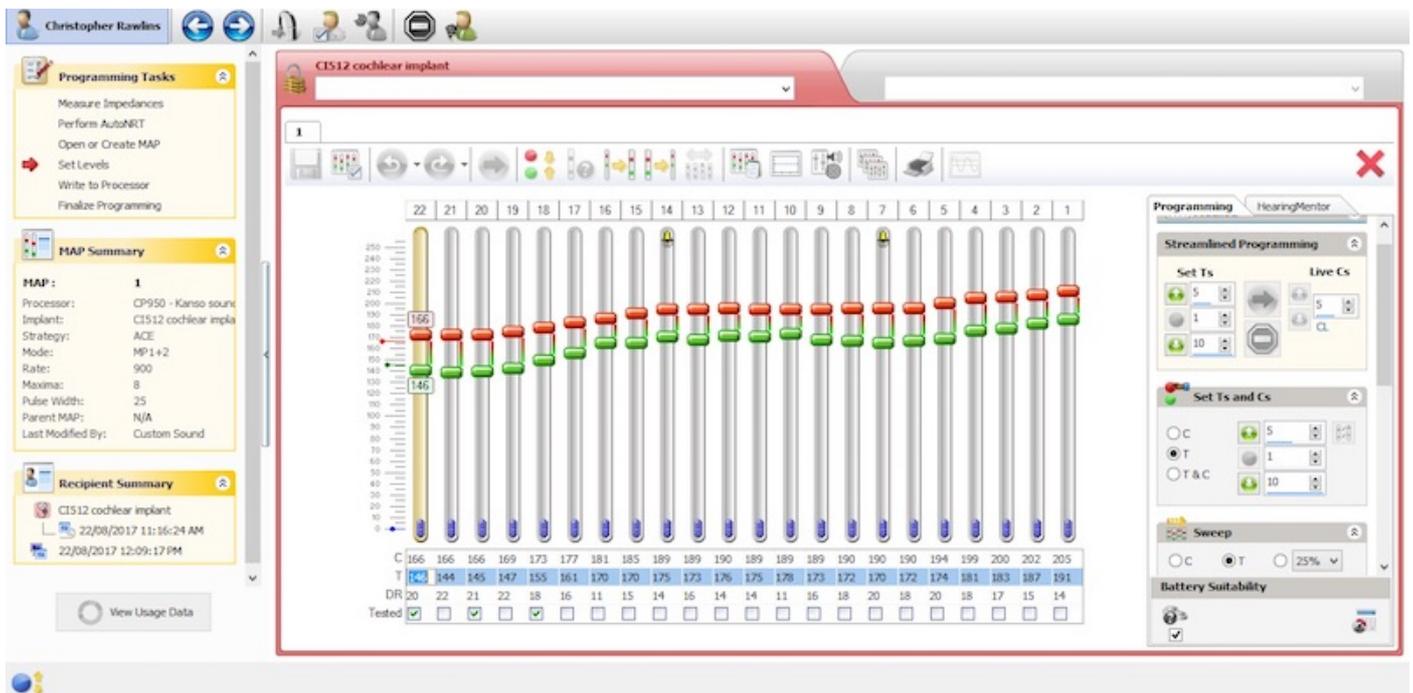
The Audiologist tested different sounds to make sure it was comfortable for me.

Then we had the big occasion of switching the processor on for me.

A JUMBLED NOISE was my thoughts.

As we chatted I could understand speech through the pops and whistles.

After about 5 minutes I was chatting with the Audiologist, it wasn't clear but I could understand her. My voice was very loud.



Screen shot of first mapping session



The Speech processor is a Cochlear Kanso

A safety cord and hair clip was fitted to the Kanso.

The drive after the appointment was full of surprises with the blinker sound clicking away and a strange whistle that I kept hearing. It was us breathing.

During the afternoon we went for a walk just hearing the passing cars and birds. In the evening I sat outside with a glass or two of wine identifying sounds and birds. The next morning on fitting the processor I found my voice to be very clear. Having the hearing aid in my left ear is helping with conversation.

My wife commented that the volume of my voice when talking had dropped.

Mapping session 3.

We went through the lower sound input levels and then the higher acceptable limits. This time I set the higher notes a bit lower and now more comfortable.

I now have three programs on remote control.

1. normal use
2. noisy environments like shopping centres
3. one on one conversation as in a restaurant or coffee shop where I can turn rear microphone off to cut background noise.

I am understanding music better and TV is clearer although without hearing aid in left ear I am getting a lot of ghosting echo.

I am identifying birds by sound easily even if not crisp & clear yet.

I now have a few days until my next mapping session so I am hoping it will improve further before then.

It is now only 5 days since switch on and I am very happy with my progress.

We went to friends for dinner on Friday night.

Eight sitting around the table and I followed conversation and communication was easy.

Saturday night we sat down to a football match on TV.

I could follow most of commentary.

Sunday nights game was different and I could not follow commentary with different TV and surround sound coupled with crowd noise.

Mapping session 4.

We went through the range of notes for lowest input I could hear and then the maximum I could stand.

I pumped up the volume.

I am now hearing a lot more of the normal sounds.

TV is clearer, birds are loud & music is getting much better.

Mapping session 5.

Back in the SACIC rooms I was once again tested by the Audiologist for lowest sounds and then the highest sounds.

We discussed the fact that I had set the volumes too high and proceeded to lower input levels of higher notes and increased a few of the lower notes..

I was tested on sentences with only one word missed.

Audiologist was amazed at my progress just a week after initial switch on.
I was given another program for music

I am now hearing much better.

Birds are now clearer and I am understanding TV much better.

It seems as if my brain resets to sound overnight with clearer hearing at fitting Kanso speech processor in mornings.

We have now returned home to Broken Hill for a week before we return for another mapping session.

We have hundreds of sparrows and I think all have a different chirp.

Today I am finding the input very loud and wind noise in microphones driving me crazy.

Now 13 days since initial switch on.

This morning I had trouble with the Telecoil switching on from a button press ?

Not long after I got the two beeps (Change batteries). All good after a quick change.

This morning I heard Battery Clock ticking.

Blackbird singing is not really clear but easily recognised.

Day 15 after initial switch on.

I had to change batteries again at 12pm last night.

It is very windy in Broken Hill today and I am being tested.

Wife & I went on business & I had trouble in Office.

We went outside & street noise was terrible.

At home cars in street outside home very loud so I turned hearing aid in left ear down 5 steps. More comfortable but missing out on wife's return home.

Sitting outside & I am getting a strange BEEP.

I have no idea what it is yet but there are about 15 Galahs in a tree up the street.

I have sent Cochlear Australia a suggestion for a case to carry remote control, batteries & screwdriver.

Day 16 after Initial Switch-on.

I have been hearing impaired for so long, I don't know normal sound volume.

I can hear my boots on carpet, cat licking it's fur and cars half a block away.

When I turn hearing aid on, I can hear it playing the turn on tune

I left my hearing aid out this morning for a couple of hours. Missing bass tones.

Day 17 after initial switch-on

I went for a drive in car and put my music CD on.

I could hear the songs very clearly and sang along. YAAAY

More no hearing aid time this morning.

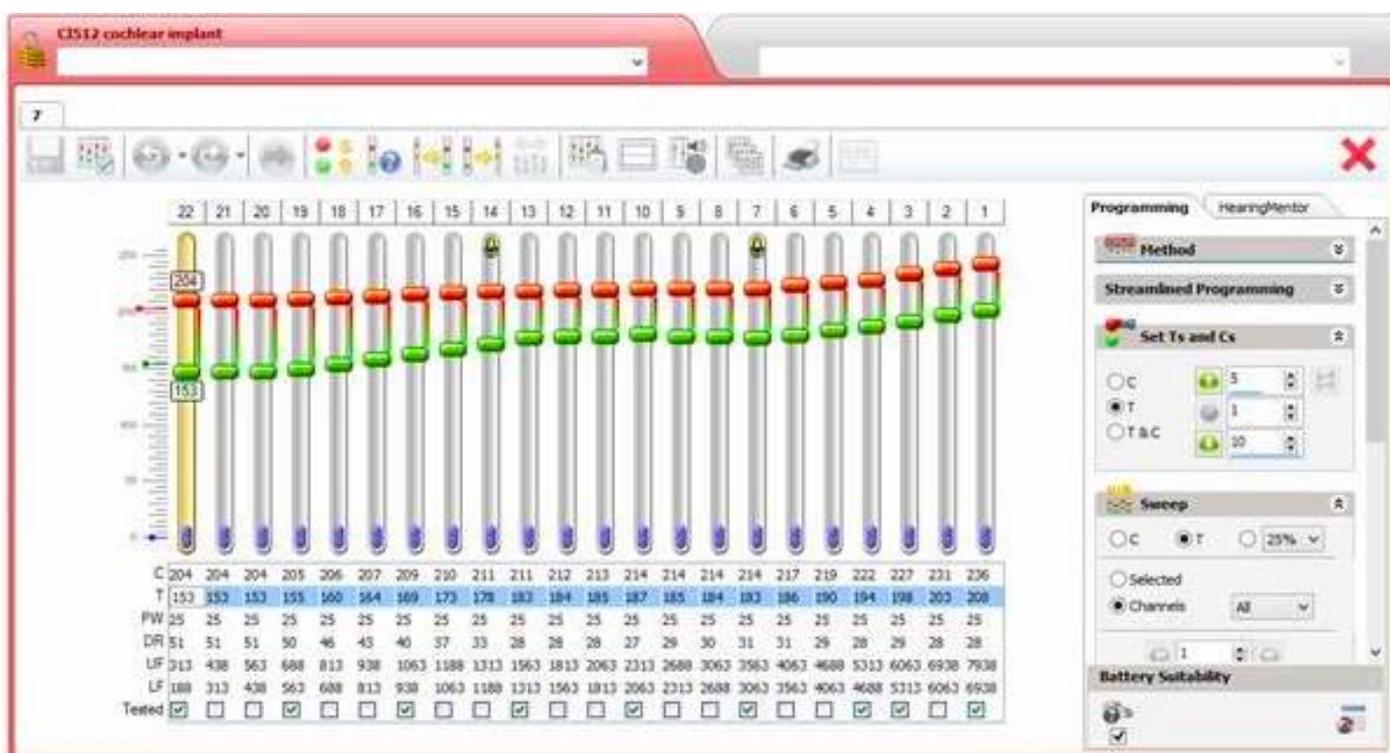
Without it I am getting ghosting echos but I think it is improving.

Final Mapping session

We did the tests and did minor adjustments to some of the mid notes.

Raising a couple of the lower notes has given me a better balance with hearing aid.

Audiologist very happy with my test scores.



Screen shot of final switch-on mapping session

I am very happy with Implant volume and hearing now.

I can now leave hearing aid out but it does help with lower tones.

I will stop writing the story at this point as it's now a lifelong journey.

You will hear new sounds as you go and your brain needs to learn what it is you are hearing.

Every recognised sound is another milestone.

Just to hear the cat licking it's fur was a truly exciting experience.

Will I go Bi-lateral Implants ?

I will not even consider it for the next 18 months to allow this implant to be fully tuned.

Then I will look at all the facts as given by Australian Hearing Audiologists, ENT Surgeon Michael Schultz, SACIC and Cochlear Australia.

Money

What did it all cost.

Thanks to Medicare, Bupa and our sickness fund most of the expenses were covered. Being a prosthetic aid, the device cost is covered by health funds.

If you are a pensioner, contact Centrelink to find out if you are eligible for Medicare Safetynet.

Don't be scared to ask how much it will cost & if there are any reimbursements you may qualify for.

Problems

What did I find wrong with the Kanso.

The Kanso uses round batteries that only last two days.

It is a must to carry spare batteries and small screw driver to unlock battery compartment with you. I am using a cliplock hearing aid case with 4 Kanso Batteries, Screwdriver and some hearing aid batteries. *Cochlear could consider an accessory to do this.*

Wind noise in Microphones is a problem but the scan function built in should reduce it to acceptable levels.

I can no longer wear my wide brimmed hat as the rim pushes the Kanso off.

I found Baseball caps in K Mart for \$5 that fit over the Kanso and hide the fact that I am wearing one.

You can get other caps with mesh sides if you think the cap may interfere with what you can hear.

You may also get a bandana that will do the job.

For those not blessed with remaining hair, the hair clip is useless. You can use a collar clip that will stop you from losing your speech processor.

Cochlear have a headband accessory that will retain your Kanso during sport
<https://store.mycochlear.com/store/index.php/aub2c/cochlear-implants/kanso/cochlear-headband-apac.html>

Thanks

In closing My Implant Journey I must thank those responsible the Journey.

My Wife

We have gone through very trying and frustrating times before the implant.

To my astonishment, Maxine handled everything in her stride.

She had to talk to doctors, make bookings and even drive 500 kms home after my operation.

Since my switch on our lives have changed and we have a renewed marriage.

Thank You.

My Family

To all those who I couldn't converse with and ignored, I hear you now.

Thank You for still being here.

Australian Hearing Staff

Charyse from Adelaide, Thank you for your counselling.

Anthony, driver of the Hearing Bus from Adelaide, Thank you for your assistance.

Sharon, Rosanna and Alesia from Broken Hill clinic, I thank you for your tests, assistance and support.

ENT Surgeons

Dr Alethea Grobler, Thank you for your care and referral

Dr Michael Schultz, Thank you for your ability as a Top Surgeon and humour.

The Girls

Audiologist, Nurse and Office support staff.

Without your input this implant success could not happen.

I thank each and every one of you.

South Australian Cochlear Implant Centre (SACIC)

These lovely people operate as a team and do not like to be recognised singularly.

As Audiologists and office support I thank Nina, Caren, Kristan, Fleur, Alli and Michelle.

I thank you for your professionalism, caring and humour.

I know I stretched your limits but am sure that we all enjoyed my visits.

I know I did.

Did I mention My Wife ?

Thank you Maxi.

Links

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Do I recommend a Cochlear Implant

Too Bloody right I do

Remember we are all different and your results will differ from mine

I hear now. and Always